

Indiana Parent/Family 2003 Needs Assessment Survey

Summary

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During the 2003 summer, the Indiana Resource Center for Autism conducted the triennial Indiana Parent/Family Needs Assessment Survey. The purpose of the survey is to gather information about current services, school issues, the Medicaid Waiver, insurance coverage, employment issues, and the cost of private services accessed by families in the state of Indiana. The following data were compiled from the responses of 710 families of individuals with autism spectrum disorders (ASD) across the state of Indiana. Where applicable, results of the survey were compared to the results of the 1998 and 2000 Needs Assessment Survey

Participants

Sixty-seven percent of the families responding to the survey have children with autism, 18% have children with Asperger Syndrome, and 13% have children with Pervasive Developmental Disorder- Not Otherwise Specified. Sixty-three percent of the children had a secondary disability, the most common being ADHD, seizure disorder, and mental retardation. Seven percent of the families had more than one child diagnosed with an autism spectrum disorder. The average age of the children represented in the survey was 12.61 years of age. Respondents included parents, grandparents, foster parents, legal guardians, and siblings of individuals with autism spectrum disorders.

School Issues

Seventy-four percent of the children with ASD in the survey attend public schools in the state of Indiana, while 13 % attend private schools. These data show a decline in the percentage of children with ASD attending public schools as compared to the 2000 data. In 2000, 84% of the children represented in the survey attended public schools, and only 5% attended private schools. In addition, 4% of the individuals represented in the survey attend colleges or universities. In 2000, less than 1% of the participants were in higher education. When asked to rate their satisfaction with their child's educational programming, 51% of the families stated that they were either Satisfied or Very Satisfied, while 26% stated that they were either Dissatisfied or Very Dissatisfied. There was a reduction in the percentage of school aged children who were suspended in the last year as compared to the 2000 survey. In 2003, 7% of the children in the survey were suspended in the last year, while 10% were suspended in the year prior to the 2000 survey. Four percent of the children had been expelled from school (the same as 2000).

Mental Health and Legal Issues

There was a reduction in the percentage of children who required short term crisis management intervention at a hospital in the last three years (7%), as compared to the 3 years prior to the 2000 survey (10%). In addition, the 2003 Needs Assessment Survey asked families whether their son/daughter was arrested or charged with a crime in the past three years. Two percent of the families stated that their son/daughter was either arrested or charged with a crime.

Employment

For the first time, the Needs Assessment Survey asked questions specifically related to employment issues for individuals 18 years of age and older. These questions reflect the emerging needs of individuals with ASD who are transitioning from school programs to community employment. Sixty-nine percent of the individuals (over age 18) represented in the survey were unemployed, 8% work in sheltered workshops, and 23% work in community jobs. Those who are currently employed work an average of 19 hours per week and have a median annual income of \$3, 500. When asked to list the supports or services that were necessary for their son/daughter to be successful in finding and keeping a job, the majority of the respondents stated that a one-on-one job coach was essential. Social skills training was also frequently listed as a necessary support. One parent wrote regarding her son:

He has Aspergers and has a great deal of skills but does not make a good impression in an interview. We are reluctant to tell employers that he is disabled for fear they will disregard him because they don't understand his disability.

Insurance and Services

Families of individuals with ASD continue to report that they have been denied insurance coverage for their son/daughter. Twenty-seven percent of the families reported that they have been denied insurance coverage for their son/daughter in the last three years. This is down from 43% in 2000, and 48% in 1998. The families listed many reasons for insurance denial, but “pre-existing condition,” “exclusion of mental disorders,” and a specific “exclusion for autism,” were the most frequently cited reason for denial. As was the case in 2000 and 1998, Anthem/Blue Cross/Blue Shield was the provider most frequently cited by families for denying coverage. Many families reported that dealing with insurance companies is a continual struggle, as reflected in the words of two families:

Autism is considered to be a mental condition by my insurance carrier. Services such as speech and occupational therapies are covered only under medical conditions. Therefore, these and other services are not covered by my carrier.

The insurance company did not know or pretended not to know, about the new law requiring them to pay for services in our state. Was denied three times before approved. Had to refer them to the State Department of Insurance to explain law.

Medicaid Waiver

Family member were questioned about their awareness of the Medicaid Waiver program, the application process, the length of time they spent on the waiting list, and their satisfaction with waived services. Eighty-five percent of the families in the survey reported that they were aware of Medicaid Waivers. Many families described the process of applying for the Medicaid Waiver as “horrificing,” “confusing,” and “complicated.” Conflicting information from professionals and lost paperwork were common complaints from family members. Some families reported that they were denied services because their son/daughter was “too high functioning.”

I contacted DD services on May 7, 2003 to request an application for the support services waiver. I called the agency 5 times before FINALLY receiving an application in late July, 2003. I was treated awful each time I called, like I was asking for the moon when all I wanted was to be mailed an application.

We were totally clueless about how to request the Medicaid waiver. Our son was evaluated and denied due to sufficient self-help skills. We wish we could have appealed, but were not aware of the process. We had no direction or guidance. Was not at all satisfied with service.

Fifty percent of the families who applied for the waiver are currently receiving waived services. This is up significantly from the 2000 survey, when 28% of the families who applied for the waiver were receiving waived services. Families currently receiving waived services waited an average of 24 months before receiving waived services. In 2000, families waited an average of 28 months before receiving services. Although many families expressed displeasure with the application process, most families were satisfied with the services they were receiving; although the level of satisfaction has declined since 2000. Fifty percent of the families on the Medicaid Waiver stated that they were “Satisfied with the availability and quality of waived services,” down from 65% in 2000. Sixty-three percent stated that “Sufficient funds are available to purchase services,” down from 70% in 2000. Finally, 46% of families stated that there were a “sufficient number of service providers” in their area.